Wisconsin

Working With Wisconsin's Indian Health Service Clinics to Improve Race Classification on Cancer Reports for Native Americans

Public Health Problem
The Wisconsin Cancer Reporting System (WCRS) collects and maintains data on all Wisconsin residents who are diagnosed with cancer - approximately 26,000 new cases per year. Wisconsin's cancer morbidity and mortality rates are calculated annually to assess the state's cancer burden. Based on findings from studies conducted in other states that showed underreporting and misclassification of Native American/Native Indian (NA/NI) populations, WCRS was concerned that NA/NIs might be underreported or misclassified in its database, and consequently misrepresented in the burden assessments.

Taking Action
WCRS collaborated with CDC and the Indian Health Service (IHS) to link 17 years of registry data with IHS enrollment lists. The results showed that 37 percent of the cancer cases matched to IHS enrollees were misclassified as non-Native American. WCRS also participated in the Spirit of EAGLES Building Cancer Surveillance Capacity project, a collaboration among the Wisconsin Tribal Health Directors Association, the Great Lakes Inter-Tribal Council, the Mayo Clinic Cancer Center, the University of Wisconsin Comprehensive Cancer Center (UWCCC), and WCRS. Data on cancers diagnosed in 2001 at Wisconsin's 12 tribal clinics and one suburban clinic that serve the Native American population were collected directly from those facilities and matched against the WCRS registry. At the time of the study, only 50 percent of the cases had been reported by non-IHS facilities, and of those that had been reported, 25 percent were misclassified as non-Native American.

In light of those results, WCRS is now collaborating with UWCCC and Wisconsin's tribal clinics to collect data directly from those clinics on a routine basis, starting with 2004 cases, to ensure stable and accurate reporting of cancers to WCRS for the Native American population in Wisconsin. A simplified reporting form and protocols have been established and will be implemented later this year.

Implications and Impact
Accurate race reporting is crucial for monitoring health status and planning interventions for reducing cancer morbidity and mortality in Wisconsin. This collaboration will improve the data collected on the NA/NI population in Wisconsin, allowing for more accurate analysis of the cancer patterns within this population (type of cancer, how far it has spread within the body, types of treatments being offered, etc.). This model can be adopted by cancer registries in other states that may have similar challenges due to underreporting or racial misclassification.

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